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Dear Representative Angerer,

My name is Barbara Byers, and I live in Ann Arbor. I am the mother of two boys on the autism spectrum, Sam and Josh, who are 11 and 8 years old. I am writing to let you know that I am extremely appreciative of you putting together and sponsoring the bills to require insurance companies and health plans to provide coverage for diagnosis and treatment of autism. It is a travesty and a form of discrimination against our children that this exists, and I am pleased to see your legislation as a huge step in righting that wrong.

I grew up in Michigan, but lived in other places until we moved back from Texas 9 years ago, right after my older son was diagnosed with autism. I expected that Michigan would be much more progressive than Texas with regard to autism treatments, but I was sorely disappointed when I arrived here. Even to get my son's diagnosis covered, I had to go through several levels of insurance appeals. And when it came to insurance coverage of autism treatments, there was nothing.

I read up on everything possible myself, and soon discovered that Applied Behavior Analysis (ABA) had several research papers showing evidence that it was most effective when done at a high intensity and early age. Since my son was still under 3 at the time, I struggled to set up a home based program, since neither insurance nor the school system would provide what he so desperately needed. I tried to keep my job for as long as possible, since providing the therapy was so expensive, but when my second child was born, I felt I could no longer meet the demands of being a corporate manager. We were spending about \$2,000 a month to provide my older son with an ABA program of about 30 hours a week. It was also difficult to even find an experienced ABA consultant or psychologist to even provide the therapy and supervision of the home program.

Then when my second son started showing similar signs, like speech delay and social difficulties, we had to go through the whole process again. So now the bill is about \$4,000 a month, running about 25-30 hours a week for each child (after giving up my \$80,000 salary to boot).

We have been doing this for the last 6 years or so, and our family has spent over \$200,000 so far. Our boys have come so far, and we know that they would not be in full inclusion today without the ABA therapy. However, it has come at a huge price – I had to stop working, and we have had to liquidate all savings, some retirement money, and also have a large home equity loan that is growing instead of shrinking. Much needed home maintenance and improvements have gone by the wayside – we have our priorities.

We have been able to taper off some hours, but ABA is still the best way to help our boys, so we are still doing about 15 hours a week outside of school with each of them. At least we will continue until the money runs out! And I am thankful that we were able to afford to do this treatment, even though it is a stretch. Many families do not even have that choice because of the enormous expense involved.

I also work with several autism organizations where I frequently talk with parents of newly diagnosed children with autism, and it breaks my heart when I tell them what the research shows their child needs, and they have no way to pay for it. I often counsel them to move to a state with better services, if they can possibly do so. And several of my friends have moved to states where ABA is covered either through insurance, Medicaid or in the school systems.

But if we can pass this legislation, I believe it will help Michigan to become a leader in providing services for children with autism. I think school systems will be more willing to provide evidence-based treatments, if they do not have to bear the entire burden of the cost. Autism is a devastating disorder, and the various parties involved need to share in providing services – insurance companies must stop discriminating and help parents access the care they need. While the intensive interventions for autism are expensive, they are no more so than a series of chemotherapy, or surgery to correct many conditions.

Some children can become indistinguishable from their typical peers, and will be able to go to college, work, live independently, get married and have families, etc. \$2-3 million can be saved over the lifetime of these individuals. So actually, the treatments are also cost effective, besides being the right thing to do.

This is the hope I have for my children, that they will be able to realize their full potential and be as independent as possible – tax-paying citizens contributing to society and maximizing their potential in life.

Thank you again, from the bottom of my heart, for sponsoring these bills and fighting for equity and effective treatments for our children, and for caring enough to do this.

Sincerely yours,

Barb Byers
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